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ABSTRACT

The paper reports on efforts of the Thakur Hari Prasad Institute (THPI), an Indian voluntary agency, to improve services to persons with mental retardation in the developing nation of India. THPI is involved in both institutional and non-institutional activities, development of national policy, and action research. One project has provided early detection and intervention to about 500 infants and young children with handicaps through use of neuro-muscular stimulation and Montessori methods. A second project is providing early identification and intervention services to over 800 children with handicaps in 10 rural villages. This project stresses locally relevant and affordable methods. The special education program of the institute utilizes individualized education plans, instructional materials made of common household objects, and integrated services. A community based rehabilitation center is planned which will have non-professionals teaching rural oriented skills to mentally retarded persons. Vocational training programs for this population in such areas as carpentry and tailoring have also been initiated. THPI is seeking industry involvement and working for new legislation in such areas as civil rights and guardianship. A parents' movement is being encouraged as is research relevant to developing nations. Increased public awareness and personnel development are also encouraged. (DB)

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T.H.P.I. ITS ROLE IN THE REHABILITATION OF THE MENTALLY HANDICAPPED IN THE CONTEXT OF DEVELOPING COUNTRIES

PRESENTED BY

Dr. THAKUR V. HARI PRASAD

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Dr.THAKUR V. HARI PRASAD

AT THE

REHABILITATION INTERNATIONAL CONFERENCE, 1988

AT TOKYO ON 7TH SEPTEMBER, 1988.

Introduction

I will not be carrying out my responsibilities as a REPRESENTATIVE and propagator of VOLUNTARY SOCIAL ACTION MOVEMENT if I will not address the national and global challenges that we have to face in solving the problems of the mentally handicapped and their families and the community in which they live. Let me affirm right from the outset that disabled persons are only people who are "differently abled". If we do not recognize this fact and that the end result of all our efforts is to achieve equal opportunities and full community involvement by all members of our society, some of whom are people with disabilities. We have not even begun to accept our real responsibilities as politicians, experts, individuals, directors, professionals, workers, or whatever category were present when we are at this conference. As we are gathered here, we have a responsibility to share ideas and knowledge and to communicate with one another during this time we have set aside and on our return to our homes to do the same thing and provide clear-cut direction and perspective rehabilitation plan.

In my paper an attempt is to respond to certain key issue as to,

1) What could be done to ensure that the needs of the large numbers of people are met.

2) What we have done and could be done to use the incredibly valuable resource of people with disabilities, their families and communities in meeting our overall challenges.

3) What we have done and could be done to develop partnership relationship with Govt. and its many sectors to assist them to develop policies and services to meet the needs of the people we work for, when carrying out their responsibilities to all the people of the country they govern.

4) What have we done to prove the indispensable role that can be played by NGOs and voluntary social action in supplementing the efforts of Govt.

In answering these issues that we have to spend effort and time and I have discussed the programmes that require priority and special attention. Mere lip service will not help, we will have to commit ourselves to seek solutions to the major concerns of the disabled, otherwise we will denigrate our own efforts.

CONTEXTUAL BACKGROUND

This paper essentially discusses the major programmes and plans of THPI in the context of developing countries. An attempt is made to briefly

trace the contextual background in which the model systems are developed, and a few model plans are presented.

India is a developing country with a population exceeding 700 million, which makes it the second most populous country in the world. Eighty per cent of the country's population is rural. Agriculture and allied occupations provided a livelihood to most of these. Most of the people are illiterate and nearly half of them live below the poverty line. Literacy is high among men while young women it is around 19 per cent. Forty per cent of the population are children below 0-14 years. The child hood mortality rate is 154 per thousand as per the recent figures (UNICEF, 1986) the number of children enrolled in school is 107:76 (male/female) per thousand which speaks itself of the plight of young children for disadvantage in our country. Facilities for health, safe drinking water, schooling and for a decent living are scarce. The rehabilitation programmes for the mentally handicapped have to be viewed in this contextual background.

Against this backdrop, the problem of mental retardation and its magnitude need to be viewed. It is hidden reality, and it is as deeply felt as any other disability. As is well known, a nation-wide estimate of the magnitude of the problem is not available, however the data from the available studies

which indicate a prevalence of 2 to 3 per cent, the number of mentally retarded in our country has been reasonably estimated to be nearly 18 to 20 million individuals. It has also been estimated that 75 per cent of the mentally retarded population are only mildly retarded, and the 20 per cent moderately retarded and 5 per cent beyond any hope who need custodial care which means around 95 per cent mentally retarded children can be helped to function independently and around 75 percent can be helped to function nearer to normal with necessary help. These glaring figures indicate the population of retarded to be helped with training facilities viz., day care, training centres, vocational training centres, sheltered workshop, integrated schooling and residential care facilities.

We are also very well aware of the fact that the services available to confront and combat this problem of tremendous magnitude, are grossly disproportionate in terms of personnel and resources. To date there are 150 known institutions in the country and their services could hardly cater to about 1 per cent of the retarded population. Then the fact also remain that the prevalence of mental retardation is high in the rural area when compared to the urban area, whereas these services available are primarily concertratd in the urban areas. The problem of mental retardation in the rural

area is almost completely ignored.

The advanced knowledge in science and technology has made the care, treatment, rehabilition and prevention of mental retardation possible to us. But the hurdle lies in the economic constraints of our country to reach the 18 to 20 million population of mentally retarded with this specialized care. The most of launching such sophisticated programm is astronomical even for rich countries. There is also the problem of logistics: we have to wait for centuries before we have enough specialied personnel, say, 1,80,000 trained special teachers, to attack the fringes of the problem. Moreover the trained personnel continue to be absorbed by the cities. It is in this context, low cost programmes aim at the large majority of the mentally retarded are considered realistic and pragmatic. This approach anticipates the involvement of non-professionals who would carry out the programme with minimum training, maximum man power development and utilisation of available infrastructure.

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ROLE OF THAKUR HARI PRASAD INSTITUTE

Thakur Hari Prasad Institute as a responsible voluntary body has been addressing itself to two major challenges: Annihilitation of the sufferings of the Mentally Handicapped and their families and two, our contribution to the rehabilitation field of mentally handicapped in terms of methods, techniques and models of care, keeping in view the needs and constraints of a developing country like ours. These issues we have tried to respond in our own very humble ways with the technical know how available with us during the last 20 years we have been successful in many ways and perhaps unsuccessful in certain ways. We may not have been very systematic and professional in our programmes but our goal throughout has been and is to reach the professional perfection, and our attempts are sincere, and we are confident that with the present onward movement and the commitment of the working team of Thakur Hari Prasad Institute, the attainment of our goals is not beyond reach. An attempt is made here to briefly discuss about the various rehabilitation services and programmes of our institute in the context of its relevance and scope of the developing country like ours. An attempt is made to schematise the various programmes and activities of the institute as given below.

Essentially THPI rests on 3 major pillars as shown in

figure-1 - i.e. (1) Institutional and non-Institutional activities, (2) National Policy (3) Action Research. A humble attempt is made to discuss the major programmes and activities.

EARLY DETECTION AND INTERVENTION

We have tried to implement this programme at institutional level and non-institutional level. At the Institutional level we run the Research and Development Project "Surya Jyothi" in collaboration with the German experts. The main focus of this project is on early detection, early intervention and early social integration of infants and children afflicted with or threatened by mental, Physical or multiple handicaps, on the model of the work done in Munich -- identification through Kinesiological/Postural reactions and therapy through Neuro-muscular stimulation using specific exercises. Subsequent integration is done through montessori environment. This project has been going on for the last 3 years and the results are quite encouraging. The total number of children that have been helped by this programme are around 500. Parents of handicapped children are immensely happy and gratified with the improvement in their children. The project has aroused keen interest in professionals working in this field in India.

The basic promise of their therapy is that the brain nerves controlling the various neuro-muscular

function of the body can be manipulated/stimulated for normal functioning if it could be done within the first five years of the child and the results are more promising if the disability is detected as early as the first 3 months.

It is well known that in a country like ours where the facilities for rehabilitation of the disabled are scarce and not given due attention,, we felt that it is our duty to spread this message of early detection and intervention. It has a tremendous impact on the cost of rehabilitation too, once the disability has crossed the critical period.

For the same reason we felt that it is our commitment to the nation to spread this movement as quickly and as widely as possible. With this in view two training courses one in Developmental Therapy for three months from Physio Occupational therapists hailing from different states and another one for 21 paediatricians were conducted. A symposium on Developmental Therapy has also been conducted in which 70 delegates from all over the country participated. We plan to conduct many such training programmes in future too. Negotiations are also being done with the University of Health Sciences in Andhra Pradesh, to get this Developmental Rehabilitation incorporated in their Medical curriculum.

The second major project on Early Detection named "Anveshana", Early Detection and Integration was carried

out in the neighbouring rural areas in a little different manner. This project was carried out in collaboration with UNICEF. The basic aim of this project is prevention, early detection and management of disability among 0-5, children WITHIN THE EXISTING INFRASTRUCTURE OF THE COMMUNITY. This project was also carried out successfully during the course of last 3 years in 10 villages consisting of a total child population 7086. Around 801 children were identified with various disabilities and among this nearly fifty percent belonged to the 0-5 age-group. The break-up of the data is included in appendix-1. These children were helped through 10 trained balwadi teachers and 10 trained mothers, (who served as the grass root level) workers) with the periodical guidance, consultation and (sometimes direct service which is followed up by the grass root level workers) by the Clinical experts of THPI. Very simple methods of care and management were taught to them - whcih are locally relevant and affordable - details are mentioned in Appendix-2. It has been proved beyond doubt that prevention and early management of childhood disability is not only possible but could be carried out with increasing efficiency with minimum technical inputs and maximum utilisation of existing manpower and material resources. The rehabilitation of disabled children can effectively carried out through home-bound package programmes. With

the confidence and experience gained from this project, the programme has already been extended to another 13 villages, it is difficult to measure the impact of a project, especially where programmes are preventive and educational. However it can be evaluated in terms of;

1) The number of cases for which services, and training programmes were provided and necessary follow up action taken.
2) Change in family attitudes and practices that are harmful or impeding the progress.
3) The level of awareness of the nature, needs and services for the disabled.
4) The amount of community participation generated.
5) The self-reliance of the project.

Results are shown in Appendix.

SPECIAL EDUCATION PROGRAMME

With regard to the special Education of the Mentally Handicapped we follow the standard methods of setting individualized education plan (IEPs) and evaluating it over a period of time, on the basis of which future goals are set. Needless to say that team work is followed in its strict sense in the assessment, planning and evaluation of children. One significant aspect of our Special Education Programme is the preparation of teaching aids out of low cost and locally available materials. Teaching aids are prepared out of waste materials such as cool drink bottle lids, seeds,

egg shells, waste papers, pencil cuttings, newspaper and magazine cuttings, materials of daily use, etc. Natural environmental materials also used to teach the children various concepts of daily living. It is striking to note that a daughter of a vegetable vendor was taught the basic concept of colour, shape, small, number etc., with the help of just vegetables. She is also taught the alphabets with the help of vegetable seeds that she is a familiar with and is easily available in her surroundings. With this approach even her mother has not found any difficulty in continuing the training at home. This principle is followed in the preparation of assessment kits and various therapeutic equipment. The idea behind this is to simplify the education materials so that the training of the mentally handicapped is possible and feasible to any one who wants to do it. This would also make the training of the handicapped accessible to all sections like--rich, poor, rural and urban. We intend to develop a resource centre for the same, so that these techniques and methods could be shared with others.

We have also learned that education need not be imparted in concrete buildings but can be effectively carried out in huts with thatched roofs which can be adopted in any settings.

INTEGRATED EDUCATION:

While trying for excellence in the field of

Special Education we are also very keenly aware and sensitive to the global challenge for integration/mainstreaming and/normalization. We may be questioned ----- why excellence at the risk of segregation. We have tried to answer this question in our own way. The various methods of integration may be varied from full integration into an everyday class room, to, partial with the class room for special services, to, special units functioning as parts of regular schools with integrated services, to, special schools of all handicapped classes. The challenge of integration is to transfer the best elements of special education to the ordinary school so that both are enjanced and so that the children benefit both socially and educationally. Countries that have little or no educational facilities for children with mental handicap have a number of possibilities open to them ----- but what is required is the will and determination to train and launch this programme. Stray efforts have been made here and there in our country and most of the efforts have met with failure. The lessons learned as per the studies launched by NCERT is that the failure is not due to faulty models, but due to the lack of clear idea/vision commitment and preserverance by those who implemented it.

We plan to adapt existing special facilities to the requirements of promoting the integration of the handicapped children with the normals in other words

using special schools as resource centres. We have tried to establish a network of links with the ordinary schools. It implies that planned and regular links were developed between the special school and neighbourhood ordinary schools. For example, teachers from two schools work together to ensure that children from the special schools spend increasing periods of time in the ordinary schools. Similarly there could be a system of planned mutual exchanges between the staff special schools and ordinary schools. Our hands are still young at it and we hope that this system will work out well to the advantages of the handicapped child, normal child, society and community in general.

The global challenge we face more than the system of integrations is not HOW to integrate but WHEN AND WHOM to integrate. As we know as the severity of disability increases the possibilities of functional integration will become thinner and thinner. But the challenge remains at the "WHEN" level. The EARLIEST the integration takes place the best ----- the most critical period being the first five years of the child ----so the question of segregation and later integration do not arise at all. We have tried to integrate handicapped young children with the normals through montessori method in the urban sector and balwadis in the rural set-ups. The results are quite encouraging ---so much so that a handicapped child is hard to be

identified by a stranger. This experiment demands for longitudinal studies on the basis of which scientific principles can be laid down.

COMMUNITY-BASED REHABILITATION CENTRE (CBRC)

We are keenly aware that the existing services do not answer the needs of the mentally handicapped in the rural areas that constitute 70 per cent of the problem. The need for training, manpower development and divising local methods of training and integration is immense. Overwhelming evidences show that CBRC is the only answer to this problem, though we do not have much experience specifically with the mentally handicapped. Very little knowledge and technical know-how is available regarding such programmes carried out in our country. But we are convinced that it has to be done and we have to make a beginning some where. We have decided to start our first CBRC at Rajhmundry. Our plan is to develop a model rural centre in lines with the THPI urban model with regard to the type of services offered, the methods and strategy employed will be adapted to local needs, situations and affordability. For example, in the CBRC rural oriented skills such as farming, gardening, poultry, diary gracing,weaving etc. will be taken up. This programme anticipates the involvement of non-professionals who would carry out the programme with minimum training. The major tasks of the CBRCs will be

1) Setting up of a model centre
2) Training of the required manpower
3) Service delivery system
4) Evaluation and Replication.

A model plan of the CBR is presented in Appendix-3. The details of manpower development and its process of implementation is discussed in Appendix-3(a) and (b).

SCOPE OF THE PROJECT:

The main objective of the project as envisaged is to evolve a comprehensive and integrated community approach to the rehabilitation of the mentally retarded children in our country: and that at the same time the delivery system should be appropriately oriented to reach the rural population at a minimum cost with dependence on a few specialists as possible. In this approach the average time spent by the specialists in dealing directly with a few mentally retarded children can be diverted to the training of ancillary professionals and other workers who in turn could train and manage many more mentally retarded children in the community with necessary guidance. In this, the efforts and time of our professionals could be stretched to the maximum use.

Our initial target is to cover a population of one lakh each in 3 districts through our model centres, which is nearly onefourth of the population in the designated areas viz. Eluru, Tirupathi and Rajahmundry

which have a total population of 11,07,327. These centres will become the model centres to extend the community-based rehabilitation care throughout Andhra Pradesh, to the mentally retarded. This is possible since these centres represent the three regions of Andhra Pradesh namely, coastal Andhra, Telangana and Rayalaseema.

Given the prevalence rate of 3 to 4 per cent mentally retarded in our population. We can expect around 3500 mentally retarded children in each of our target areas. There will be roughly around 38,756 retarded children in the designated areas that the project aims to reach with the rehabilitation services. Though this model we expect to bring down the cost for the care of the mentally retarded considerably to the minimum possible extent in terms of manpower, material resources and financial implications, with major thrust on utilisation of available local resources manpower and expertise. This project if found successful in the rehabilitation of the mentally retarded on a cost-effective basis as envisaged through trained "Balasevikas", it could be recommended as a model for the community care of mentally retarded throughout our country.

VOCATIONAL REHABILITATION FOR THE MENTALLY HANDICAPPED

Another major challenge that we face is in the vocational rehabilitation of the mentally handicapped. Having a job or being gainfully employed fulfills an

important human need as it instills confidence in himself and confirms his ability to care for himself if not his family. This need is particularly strong among disabled persons. In developed countries it is relatively easy to help the disabled person achieve this sense of independence and social usefulness. In developing countries, however, and particularly in the most rural and depressed areas of such countries, where resource are scarce and professional help and specialized rehabilitation centres non-existent, the situation is much more difficult if not seemingly impossible.

India has the largest number of disabled persons. We, therefore, have to see how best this section of 10 per cent India's total population can be rehabilitated. In India we have not been able to eradicate the basic problem --- unemployment, poverty and sub human living conditions despite our impressive advance in science and technology. Disabled suffer more because the science and technology have not been harnessed to make them mobile and productive. It is in this context the need to demystify the rehabilitation process is called for.

With this in view we have started vocational training in 1) Carpentry, 2) Tailoring 3) Crafts 4) Candel-making 5) Caning 6) Book binding and 7)Home management. Our aim is to make these children self dependent.

Once the children master in a particular activity they are given independent tasks. They are also given renumeration for their completed tasks. We are glad to note that some of our children have opened accounts in "Kiddi Bank" and started saving up the renumeration they get. We plan to introduce rural oriented skills like gardening, farming, poultry-keeping, dairy farm management etc.

In addition we are providing training to work/help in hotels, to attend to telephone calls, to run errands, to assist in kirana-shops, workshops etc.

Around 60 children of age ranging from 16 to 32 are being trained in this unit. We strive not just to train fifty or sixty children and be content with that. Our aim is to evolve a system of vocational training and placement on the basis of following criteria:

1) Simple and low-cost methods
2) Skills that are in demand in the open market
3) Skills that give tangential and/economic reward.
4) Availability of raw materials.
5) Skills training that is economical and suits our socio economic context.

In order to help us out with the vocationalisation of mentally handicapped a council is formed with the members from the faculty of THPI, parents of the mentally handicapped and a few prospective employers. We feel that it is a significant step we have taken in

the direction of evolving a suitable module for the training of children in our set-up.

One major task ahead is to identify the jobs that are relevant to our set-up. In our set-up agricultural farm will provide an useful manner. Viewed in the perspective of industrialised countries, the idea of placing mentally retarded individuals to work in unskilled jobs in hotels and farms or any domestic services may look out-dated and out moded. However in our Indian context this type of employment is in line with needs of the society in which the handicapped persons live.

ROLE OF INDUSTRY IN THE INCOME-GENERATION:

Another major role we have to play is to be a pressure group in seeking industries co-operation. Both the public and private industries can play considerable role in assisting the disabled in all forms of employment for generation of income to the disabled persons. In addition to providing jobs for disable in their own industries, the industries can provide enclave employment where group of disabled persons work as separate units under special supervision. They can help in numerous other ways such as providing simple home-bound work, help in the supply of raw materials to the disabled engaged in self-employment, marketing the products prepared by them and so on. The government may also consider subsidies and special incentives to those

employers who could place a certain number of handicapped persons, and adapt their technology and working environment to suit the requirements of the handicapped-

No doubt the success of any vocational training programme is eventually reflected in the total number of handicapped persons placed in gainful employment. In the entire country at present--especially with its vast reservoir of normal unemployed persons-- suitable patterns of vocational guidance, training and placement do not exist. Atleast for the purpose of eradicating the sufferings of some of the families who feel this absence most, these centres are to be developed.

NATIONAL POLICY FOR THE MENTALLY HANDICAPPED.

In the Indian context, strictly speaking, there is no law which exists for the welfare and protection of the mentally retarded citizens. The Indian Lunacy Act of 1912 makes a mention of the mentally retarded, but clubs them together with the mentally ill. The Indian Lunacy Act has not showed any changes from the time of its enactment. The law therefore is non-utilitarian and archaic. A new law is definitely called for. This has to be carefully planned because it is not enough if one institutionalises certain concepts by way of a law, for real social change, reform and advancement, it is the internalisation of concepts that is more important. The law has to be one that takes into consideration the social exigencies as well as the contemporary Indian

situation as it exists.

One of the outcomes of the advancement in the field of medicine is the accompanying longevity in the people as a whole which includes the mentally retarded individuals. The mentally retarded tend to live a full span of their life, and one of the problems that is faced by many of the parents, is the provision to care for their mentally retarded wards after the demise of the parents. This problem becomes all the more acute because of the social change that is occuring in India due to industrialisation as well as urbanisation and the resultant loosening in the family system that existed. The joint family system had its own defects, yet provided a social cover for the worker or the handicapped members in the family. In the modern context this role, which was previously taken by the family, is to be institutionalised and eminent persons have advocated a Guardianship plan for the mentally retarded. This is the main involves the saving of certain amount of money over a fairly long period of time by the parents during their lifetime to look after their handicapped ward after their demise. The funds generated are handed over to a lawfully established Trust. The Govt. of India is already contemplating National Trust for Welfare of the MentallyPHandicapped in difference to the recommendation of all India Seminar conducted by THPI, so that they take upon themselves the responsibility of looking after the retarded person during the entire life span of the retarded citizen through one of the institutions

run by it. This is an essential need that is felt by many of the parents and would go a long way in ameliorating the anxieties of many of them.

Moreover, the mentally retarded individuals present a very wide range of problems which differ both in their nature and complexity. As such, different types of services - medical, educational, social welfare and employment - are required by them. The planning and development of a programme and its coordination is a major administrative problem. This is so because in the Indian setting different ministries - Health, Education, Social Welfare and Labour - are concerned with the area. All these being "State subjects", the issue becomes more complicated as each State can evolve its own policies and programmes. This can bring about extreme differences in the services provided or the stress placed in different States. A vital step, therefore, is to evolve a national plan for the welfare of the mentally retarded persons.

THPI took the responsibility of evolving a national plan for the mentally handicapped in our country and with this purpose a national seminar was organised in February 1987 in which representatives from the concerned Ministries, Central Government, State Governments, professionals, Voluntary Organisations Parents participated and reached consensus regarding the various aspects that should go into the policy paper. The policy paper covers all the aspects of mentally handicap

under the three major heads: 1) Prevention and Health 2) Education and Vocational training and 3) Social Security.

This policy-document was released by our Prime Minister on Jan. 14th 1988 and was presented to all the concerned functionaries including planning commission. An inter-ministeria committee has been constituted to work out the details of the policy, and a seperate committee on Legislation to work out the details of the formulation of a National Trust for the Mentally Handicapped.

It is indeed a Spectacular accomplishment of the voluntary social action that has happened for the first time in the country. We could hopefully feel that the happiness is on the menu of the mentally handicapped.

Since there is a total vacum that no model agency at the national level is functioning as a representative body to plead for the cause of the mentally retarded, the seminar made a recommendation to form a National Forum for the Welfare of the Mentally Handicapped. The THPI took initiative as a chief promoter by taking upon itself the responsibility by constituting the NATIONAL FORUM FOR THE WELFARE OF THE MENTALLY HANDICAPPED, which will play a vital role by becomming a bridge between NGOs working in the field of the Mentally Handicapped and the Government. The National Forum so formed and has received affiliationxstatus by the ILSMH.

PARENTS MOVEMENT

It is unfebatable fact that the high potency for

The rehabilitation and subsequent normalisation lies in the family and community and therefore these units should be the base for any therapeutic programmes. The very disability is germinated from the family and community and no programmes can ever be as effective as that which involve the family and community.

We need to tap this imminent force and how do we do it. We need to develop general awareness among parents and families that human disability can be either be cured, prevented or arrested from further progression. Once a disability has occured it must be detected early, its nature and extent must be assessed and they should be given early infant stimulation so that further handicap can be totally averted. Once disabled, they should be examined and given training that suit their potential, capacities and needs and enable them to develop their skills so that they can become self dependent. To make these things possible it is imperative that deliberate efforts are made in order to involve the parents and family members in a planned and systematic manner. This programme also envisages the need for parents training.

Essentially, the parent training programmes aim to take parents as partners in care. They also transfer the special skills of care to the parents. Following short periods of few weeks to few months, these programmes have shown how effective parents can be in the care of their handicapped children. This approach

not only allows for the ideal utilisations of centralised facilities but also change the available persons with appropriate skills for care of the mentally handicapped.

The self help group movement is an expression of the potentials for helping each other among families with mentally handicapped individuals. This movement allows for services to develop within the homes and in small communities without excessive amounts of professional inputs.

This parent group which will initially be based in the twin cities will expand itself to the nearby districts and in the long run to the whole of Andhra Pradesh State. This body should be able to assume independent character over a period of three years and take up various programmes aimed at prevention and rehabilitation of the disabled. To start with we have two active parents groups in the institute--one a self-help group and another parent's group for the vocationalisation of the Mentally Handicapped. This group will form the base.

RESEARCH PROGRAMMES

Research is an integral factor and plays a crucial role in the development and formation of any programmes on scientific lines. Apart from the various research programmes that are being carried out in our Surya Jyothi Project and Anveshana Project. We feel there is

an enormous amount of work which needs to be done among which a few important areas that are of immediate concern are noted here:

1) To bring out a profile of the mentally handicapped and their families who sought professional help in our set-up. This will be on the basis of the rich data that our records hold. Such a study will provide valuable feedback for our community awareness building programmes and various community based care programmes.

2) Our Indian families have tremendous resources and man power embedded in them for the rehabilitation of the mentally handicapped such as grand parents, sibblings etc. The necessities of life force both parents to go out for job whether in the rural area or urban area, with little time even to cater to the needs of the normal children. More so they tend to neglect the handicapped children as they feel that the returns are less. It is in this context the training of sibblings and grand parents and other family members who could spare time for the training of the handicapped, child arises. With this in view we plan to undertake an experimental study of involving sibblings in the care and training of the mentally handicapped on the basis of which strategies can be worked for future.

3) It is planned to undertake a comparative study of the impacts of the special training of the mentally handicapped children: children under fostercare home care vis-a-vis children coming from their own home.

This would help us to bring in suitable modifications in our care programmes and test the efficacy of the foster-home care.

4) We need to conduct a pilot study on the community-based rehabilitation programmes for the mentally handicapped.

5) We need to undertake a knowledge and opinion survey of the school teachers regarding the integration of the handicapped with the normals.

6) Very little is known about vocational rehabilitation. There is need for research to solve not only current problems but also those which may be anticipated. We need to collect data on the effectiveness of methods so far used. We need research in adaptation of jobs and safety of disabled workers. Adapting jobs for the disabled calls for creativity and imagination. Industries may be asked to fund such projects.

7) We need to undertake research to evolve an <u>effective media of communication</u> for awareness building.

<u>OTHER PROJECTS</u>:

The other major programmes we have in view are:

1) Time to time detection of the mentally handicapped children from the certified school for Boys and Girls and plan for their rehabilitation.

2) Education of the school teachers regarding mental handicap so that children are identified and referred to us when he/she is 8-10 years old, after 3 to 4 years

continuous failure in the 1st divisions, that is, once the critical period for intervention is over.

3) To take up some practical and viable steps towards the integration of the disabled children, especially the mentally handicapped in the normal school.

EDUCATION AND PUBLIC AWARENESS (FUTURE PLANS)

Communication is vital to detection, rehabilitation and prevention. The fact is that people with disabilities are not within the reach of available services. How are we to reach them? And how are we using the media - to reach the public - who are not directly affected but whose attitude and behaviour help determine the quality of life for people who are disabled. The answer is Education and public awareness pertaining to the prevention, facilities available for earlier intervention and rehabilitation must be provided to all people, and especially to all parents of the disabled, prospective parents and all practising professionals. Education and Public awareness will encourage self - awareness, informed decision-making and appropriate action. Such effective programmes can and do and make a dramatic difference in decreasing the incidence and prevailance of mental handicapped in our country and all over, as preventable factors contribute a larger share in the generation of disability in our country as well as other developing countries.

Young and old people must be made aware of the

Vital link between their health and the eventual health well being of their children, the hazards of early marriages consanguinous marriages that are so prevalent in our set-up etc. Prevention education can assist in ensuring that all young people will have the knowledge, awareness and attitudes necessary for responsible parenthood and preventive health care. A comprehensive prevention curriculum should be a permanent part of the State's education programme for students of all ages in public and private schools and colleges. It should be included in continuing education too.

The dissemination of knowledge should also be tailored to the needs of specific target populations--high-risk group, adolescents, low socio-economic population, slum dwellers, rural folks etc. Written and audio-visuals materials, alongwith the professional training programmes, workshops, seminars, professional publications, public service announcements, local media such as folk songs, Burakata, role-plays, media talk etc, are extremely useful in educating the public. Materials and presentation should be available in regional languages. Television and radio are excellent vehicles for reaching the general public as well as targetted populations. These public media should be considered for use in disseminating information through regular programmes during the day time and the "prime time" hours.

The challenges before as is: in determining what messages should be conveyed to what type of audience and in which form. Maximum utilization of existing communication media and conveying the correct message prosess the second major challenge to be worked out.

CAMP APPROACH:

As a process of human resource development we have conducted several Rural Camps through our Clinical Team without any expenditure through Resorce mobilisation identifying Resorce Centres Balasevika Trainees, Balwadi-Creches , Public Health Centres in collection of data dissemination of information- and supply of Health cards for further follow up.

PERSONNEL DEVELOPMENT

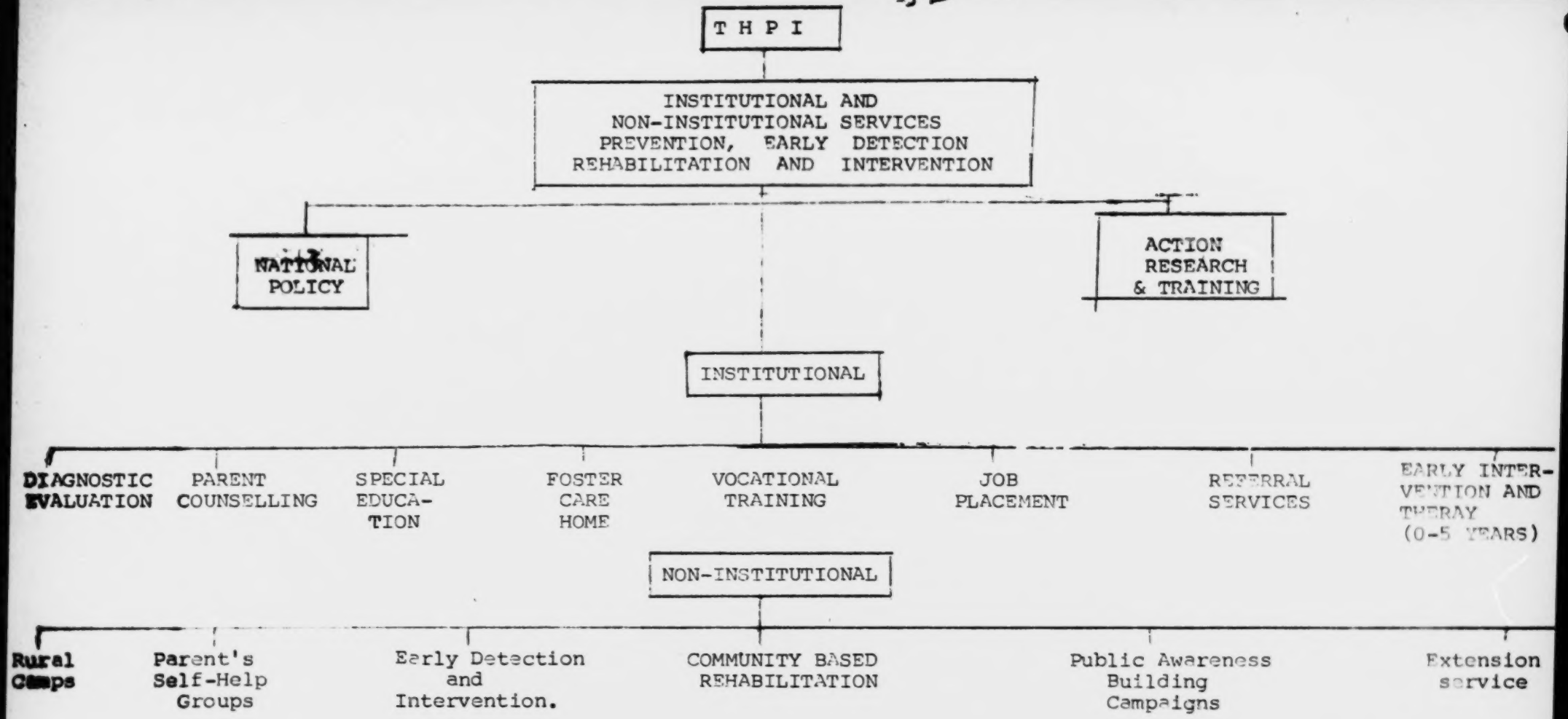
Another global challenge that we face is in the area of manpower development. For any rehabilitation plan to be effective, knowledgable and capable individuals must be available to develop, implement, and maintain that plan. The number of individuals (professionals, para-professionals and parents) currently trained in the area of prevention, intervention and rehabilitation is limited. The resources for personnel development must be identified and encouraged, the tools for training should be developed, and a proper monitoring system should be evolved.

Our immediate plans are to train the grass root level workers, the balwadi teachers, Creche Workers and

the trainers of these balwadi teachers. We also have ongoing inservice programmers to keep the knowledge and techniques of our trained personnel update and useful. A few diploma programmes to train physiotherapist in developmental therapy to spread our innovative methods on early identification is also in our plan.

CHALLENGE FOR THE FUTURE

Health promotion, prevention of diseases, early detection of disability, early intervention, rehabilitation community based care, integration of the disabled are not static processes. Its pattern of services and programmes must continue to change with the thinking and practice of future years. No simple blue-print of future development can be readily sketched at this time. Hence, no single approach to all these programmes including technology, delivery system and management would be applicable in every corner of the world. Every country should decide its own plan on the basis of its specific needs, and experiences gained from abroad and lessons learnt at home to ensure a life of dignity for the disabled. No amount of recommendations or resolution can make-up for positive action. It is necessary to prevent disability now, treat handicap immediately and train and rehabilitate the disabled today. Yes, it can be done, It requires political will, determination and clear goals and perspectives. The reality is that the attitude and vision we have determined whether we are successful in meeting the global challenges of helping the disabled, which is the reason why we are together today.


T H P I
INSTITUTIONAL AND NON-INSTITUTIONAL SERVICES PREVENTION, EARLY DETECTION REHABILITATION AND INTERVENTION
NATIONAL POLICY
ACTION RESEARCH & TRAINING
INSTITUTIONAL
DIAGNOSTIC EVALUATION
PARENT COUNSELLING
SPECIAL EDUCA-TION
FOSTER CARE HOME
VOCATIONAL TRAINING
JOB PLACEMENT
REFERRAL SERVICES
EARLY INTER-VENTION AND THERAY (0-5 YEARS)
NON-INSTITUTIONAL
Rural Camps
Parent's Self-Help Groups
Early Detection and Intervention.
COMMUNITY BASED REHABILITATION
Public Awareness Building Campaigns
Extension service

"Anveshana" - Rural Project - 1985 - 1988

RESULTS (1985 - 1988)

Total population surveyed	17671
Total families covered	2940
Total Children enumerated	7068
Total disabilities identified (Survey)	801
Other diseases	383
No. of Nutritional Disorders	382
Total disabilities in children - Followeded up	782
No. of disabilities referred to THPI Specialists for consultation	749
No. of other disabilities referred to other specialists	286
No. of disability cases treated successfully	405
Total no. of drop outs	33
Other diseases cured	203
No. of children integrated in the Balwadies	73
No. of Children in the process of integration	301
Total No. of visits by THPI team	107
Health Education camps	113
Total Women benefitted from the camps	1029

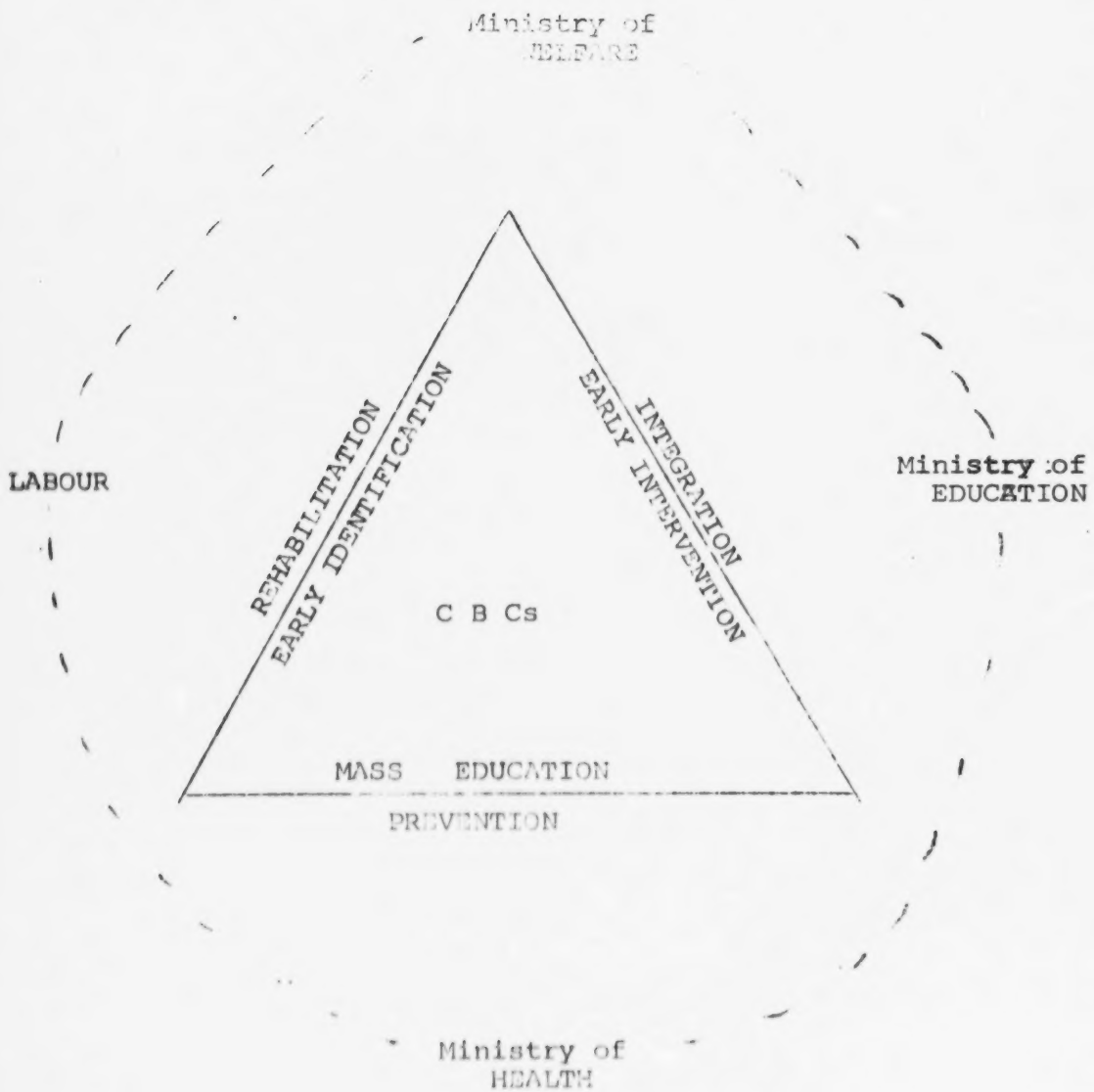
Many children we had found in danger of becoming disabled, many were cured or improved considerably or are in the process of integration and the required followup. Three children died following malnutrition and subsequent infection because the families were not interested and did not heed to our advise to get the children treated.

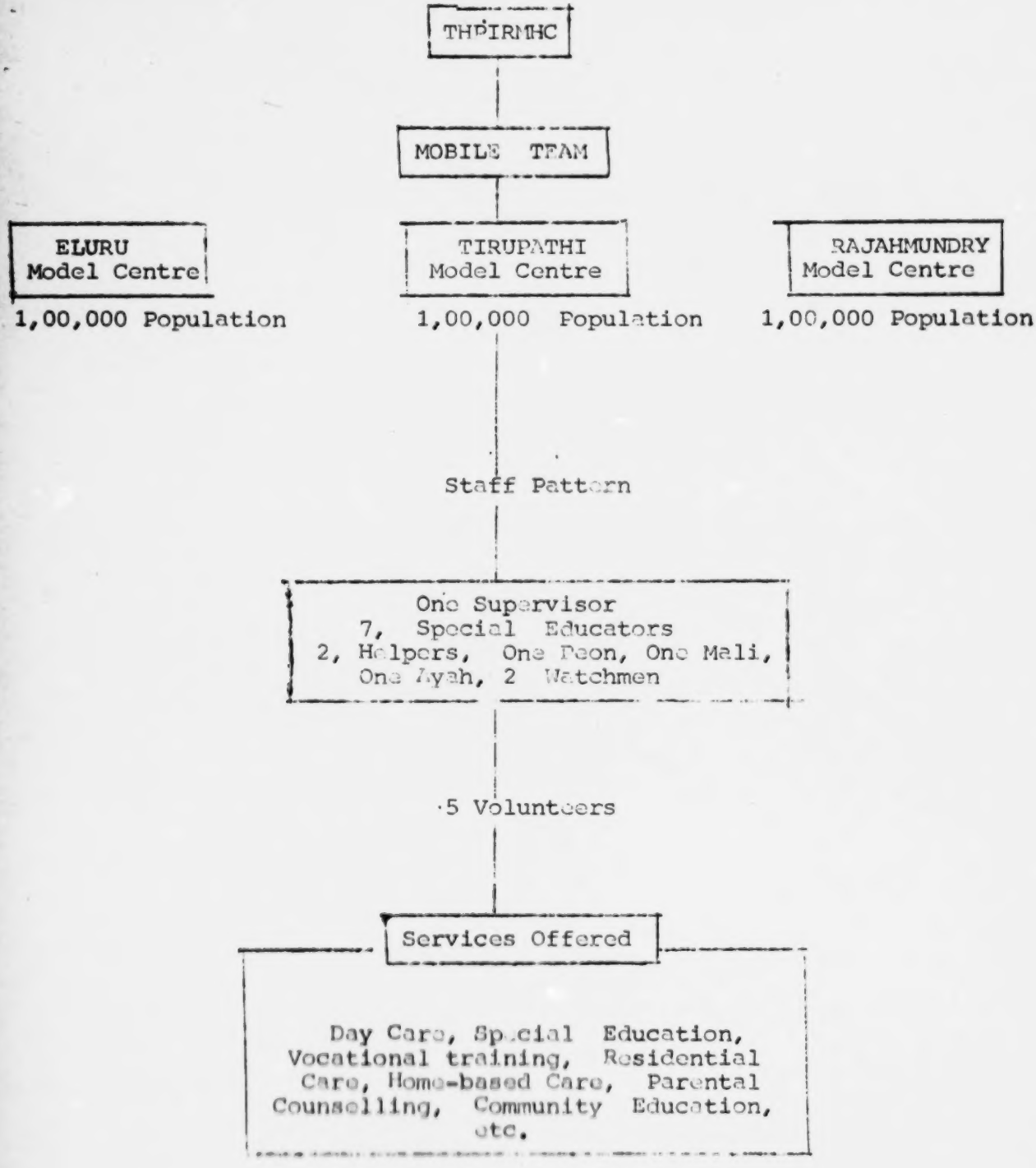
APPENDIX - 2 "ANVESHANA" PROJECT

INTERVENTION PROGRAMME IN BRIEF

	Services Provided	Person or Organisation responsible
Prevention	Immunization of all children of 0-5 years, Vit.A supplementation, nutrition education, awareness camps on the causes and prevention of disabilities among children, in particular immunization, diarrhoea management, control of Vit.A. deficiency, preparation of low cost nutritious food, proper anti-natal care and natal care, Education for pregnant and lactating Mothers etc,	District Medical and Health Services Department, local PHC, PHC Sub-Centre Community canning and preservation Centre, Home Science college Mahila Mandals, THPI team.
	1) Simple screening of all children for developmental delays, impairments and disabilities through door-to-door survey.	60 Volunteers (Balasevika Trainees) 10 Balwadi Teachers
Early Detection	2) Assessment, diagnosis and referral for treatment through mobile clinics, camps etc.	Clinical Team from THPI other Volunteers from Youth Club, & Mahila Mandals
Early Intervention	1) Treatment for general ailments and diseases	THPI Clinical Team
	2) Treatment for the disabled cases	Govt. ENT Hospital, Orthopaedic Hospital,
	3) Referral services and provision of aids of appliances	Vikalungala Corporation, Vocational Rehabilitation Centre,
	4) Spl.Education & Vocational Training for the MR	THPI, trained teachers
	5) Integration of disabled children in existing pre-school centres and schools	A.P.State Council for Child Welfare
	6) Home-based intervention and parents training programme	Training mothers & Volunteers

Model of CBRC




THPIRMHC
MOBILE TEAM
ELURU
Model Centre
1,00,000 Population
TIRUPATHI
Model Centre
1,00,000 Population
RAJAHMUNDRY
Model Centre
1,00,000 Population
Staff Pattern
One Supervisor
7, Special Educators
2, Helpers, One Peon, One Mali,
One Ayah, 2 Watchmen
5 Volunteers
Services Offered
Day Care, Special Education,
Vocational training, Residential
Care, Home-based Care, Parental
Counselling, Community Education,
etc.